Preventive Health Care for Women with Developmental Disabilities

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“Cascade of disparities” for people with developmental disabilities (Krahn et al.)

Emerging evidence: Health promotion for people with disabilities is critical yet often ignored (Rimmer et al.)

Established commitments to self-determination for people with disabilities

Little evidence of implementation in health care
Background: Cervical & Breast Cancer Screening

- Cancer screening recommendations set by the US Preventive Health Services Task Force
- Cervical cancer, once the leading cause of cancer deaths among women, is now completely treatable and preventable with Papanicolaou smear test (Pap test)
- Breast cancer: 2nd most frequently diagnosed cancer & 2nd leading cause of cancer deaths in women
- Routine mammography reduces mortality by ~20%
- Changing guidelines
  - Mammography guidelines changed in 2009 (controversial)
  - Pap test guidelines changed ~3 weeks ago
Background: Cervical & Breast Cancer Screening for U.S. Women with DD

- Existing research suggests women with developmental disabilities have among the worst rates of cervical and breast cancer screening in the United States.
  - Limitations: Self-reported or proxy-reported data
- Barriers to care
  - Women’s limited knowledge
  - Fear surrounding procedures
  - Physicians’ pejorative attitudes
- No evidence-based interventions have been established as effective in increasing women’s receipt of screening
- Our focus: Empowering women to be informed, assertive patients
Background: **Women Be Healthy**

- Health promotion intervention designed to empower women with developmental disabilities to obtain cervical and breast cancer screening

- 90-minute *psycho-educational classes*, once/weekly
  - Eighth week is graduation (7 weeks of instruction)

- Content: anatomy, cancer, importance of screenings, communicating with health care providers, field trip to GYN office

- Preliminary testing: women reported satisfaction

- Developers: Lunsky, Straiko, Armstrong; (revised by Havercamp, Dickens)
Randomized Control Trial of *Women Be Healthy*

- Evaluate intervention implementation fidelity
- Determine screening rates from medical records
- Develop recruitment & consent protocol
- Develop & test WBH2
- Examine racial disparities in screening
- Conduct feasibility & acceptability trial of WBH2
- Assess women’s accuracy in reporting procedures
- Identify screening barriers
  - Medical records
  - Family caregivers

**NIDRR Field-Initiated Research: Study & Sub-Studies**
Participants’ counties of residence

🌟 = Persistently poor counties (>20% of county with income below the federal poverty level for >30 years); 10 North Carolina counties are persistently poor
# Description of the Sample

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n = 203 women</th>
</tr>
</thead>
<tbody>
<tr>
<td>Race is Black</td>
<td>47%</td>
</tr>
<tr>
<td>Race is Asian, Native or Latina</td>
<td>3%</td>
</tr>
<tr>
<td>Has a child</td>
<td>13%</td>
</tr>
<tr>
<td>Lives alone or with partner</td>
<td>8%</td>
</tr>
<tr>
<td>Lives in formal residential setting</td>
<td>40%</td>
</tr>
<tr>
<td>Lives with family caregiver</td>
<td>45%</td>
</tr>
<tr>
<td>Age (mean)</td>
<td>40 years (19 - 71 years range)</td>
</tr>
<tr>
<td>Impairment is mild or moderate</td>
<td>91%</td>
</tr>
<tr>
<td>Lives in rural area</td>
<td>75%</td>
</tr>
<tr>
<td>Insured</td>
<td>&gt;99%</td>
</tr>
</tbody>
</table>
Goal: Determine Cervical & Breast Cancer Screening Rates

- Existing estimates of screening rates derived from self-reported or proxy-reported interview data
  - Biased reporting is highly likely by all women regardless of their disability status
  - Accuracy is unclear: women more accurate about whether they received screening than when they received screening
  - Accuracy of reporting by women with developmental disabilities has not been studied

- Obtained screening data from medical practices
  - Extraction forms: dates of Pap test, mammography, clinical breast exam, physical exam, insurance type
  - 91% response rate from 253 medical practices
  - Item non-response 6-9% for each procedure in last year analyzed
Percent of women receiving screening procedures, 2006-10

Percent of Receipt Rate

- Pap
- Mamm (≥40)
- Physical


Percent of Receipt Rate: 0, 20, 40, 60, 80, 100

Data points:
- 2006: Pap = 22, Mamm = 46, Physical = 55
- 2007: Pap = 30, Mamm = 51, Physical = 52
- 2008: Pap = 34, Mamm = 53, Physical = 64
- 2009: Pap = 29, Mamm = 46, Physical = 61
- 2010: Pap = 28, Mamm = 47, Physical = 59

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Mammography receipt among NC women ≥ 40 in 2009 or 2010

* North Carolina data from 2010 BRFSS
In multivariate analyses, White women were 5x more likely to receive mammography than Black women.
Pap test receipt among NC women \( \geq 18 \) in 2008, 2009, or 2010

* North Carolina data from 2010 BRFSS
Goal: Identify determinants of Cervical Cancer Screening

Women were more likely to receive cervical cancer screening if they:

- Lived in a residential facility (as opposed to at home with family caregiver)
- Lived in a rural area
- Received care from an OB/GYN

Parish et al, forthcoming, Public Health Reports
Goal: Test Women Be Healthy

- Randomized control trial with wait-list controls
- 21 sites across North Carolina
  - Community rehab programs
  - Community colleges
  - Other disability service provider organizations
- Pre-test, post-test interview design
  - Computer-assisted, in-person interviews
- Randomized sample at each site
- Curriculum taught by on-site instructors (not research team members)
- Post-test interviews mean of 13 days after intervention
## Knowledge at baseline and post-test (% correct)

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Control Baseline</th>
<th>Control Post-test</th>
<th>Experimental Baseline</th>
<th>Experimental Post-test</th>
<th>Odds Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Define cancer</td>
<td>39</td>
<td>42</td>
<td>32</td>
<td>39</td>
<td>NS</td>
</tr>
<tr>
<td>Define mammogram</td>
<td>45</td>
<td>48</td>
<td>41</td>
<td>55</td>
<td>2.33**</td>
</tr>
<tr>
<td>Mammogram frequency</td>
<td>22</td>
<td>21</td>
<td>15</td>
<td>29</td>
<td>3.09**</td>
</tr>
<tr>
<td>Who should do breast exam</td>
<td>90</td>
<td>89</td>
<td>90</td>
<td>91</td>
<td>NS</td>
</tr>
<tr>
<td>What should you do if find lump</td>
<td>71</td>
<td>81</td>
<td>70</td>
<td>72</td>
<td>NS</td>
</tr>
<tr>
<td>Define Pap test</td>
<td>38</td>
<td>52</td>
<td>40</td>
<td>51</td>
<td>NS</td>
</tr>
<tr>
<td>Frequency of Pap test</td>
<td>19</td>
<td>29</td>
<td>18</td>
<td>37</td>
<td>NS</td>
</tr>
<tr>
<td>Pap instrument identification</td>
<td>59</td>
<td>70</td>
<td>59</td>
<td>70</td>
<td>NS</td>
</tr>
<tr>
<td>Ways to reduce anxiety</td>
<td>41</td>
<td>48</td>
<td>43</td>
<td>58</td>
<td>NS</td>
</tr>
<tr>
<td>9-item composite (mean)</td>
<td>4.3</td>
<td>4.8</td>
<td>4.1</td>
<td>5.0</td>
<td>.38**</td>
</tr>
</tbody>
</table>

No statistically significant group differences at baseline; Odds Ratio represents significant regressions, controlling baseline knowledge; reference group is control group; red indicates significant knowledge gains within group.
Implications

- Women with developmental disabilities have low rates of cervical and breast cancer screening
- Women with developmental disabilities who live in the community have limited knowledge about cervical and breast cancer screening
- A targeted intervention, geared to learners with low literacy, can improve the knowledge about cervical and breast cancer screening of women with developmental disabilities
- Modest knowledge gains in breast cancer but not cervical cancer indicate greater duration of content related to cervical cancer is necessary
- Clear need for targeted intervention with women, caregivers, health care providers
Anecdotes & Conclusion

- Some women with ID were raped, sometimes by multiple perpetrators
- Some women had children (13% of the sample), sometimes with multiple partners
- Some women had HIV or HPV
- Many women were sexually active and/or on birth control
- Some medical providers stated that the women did not need Pap tests because of their ID

- Two physicians wrote on medical record forms “not needed because mentally retarded” [sic]

- Women with ID who live in the community are at risk for developing HPV and cervical cancer and should receive Pap tests according to clinical guidelines
Thank you!

- Participants, Advisory Board, community partner sites, instructors
- Funders: US Department of Education, NIDRR, Grant # H133G090124; NC Division of MH/DD/SAS, NC Office on Disability & Health; Lurie Institute for Disability Policy at Brandeis University
- Research team: Karen Luken, Jamie Swaine, Pam Dickens, Grace Wright, Glenna Williams, Esther Son, Sarah Dababnah, Rod Rose, Michelle Techler, Allison Ivie

For more info:  
http://lurie.brandeis.edu/women/index.html